



Commonwealth of Massachusetts
Massachusetts Developmental Disabilities Council

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Testimony of Ashley McAnespie
To the Joint Committee on Children, Families, and Persons with Disabilities
July 14th, 2015
HB 128

Good Morning Chairwoman Flanagan, Chairwoman Khan and Committee Members,

Thank you for giving me the opportunity to address you on HB 128 An Act Updating the Real Lives bill. My name is Ashley McAnespie and I am a Disability Policy Consultant at the Massachusetts Developmental Disabilities Council. The Council is federally mandated to educate policymakers on both the state and federal level about the intent of legislation and its' impact on people with Developmental Disabilities. In addition, the Council works to improve the system of supports for individuals with developmental disabilities and their families by bringing together lawmakers with advocates to make sure people with developmental disabilities are included in decisions about public policy.

HB 128 makes three changes to the Real Lives Law that was passed during the 188th legislative session.¹ First, it looks to change who can be appointed Chair of the Self-Determination Advisory Board created by the original law. The Self-Determination Advisory Board was created to advise the Department of Developmental Services "on efforts to implement, publicize, evaluate, improve and develop information regarding self-determination." Instead of having the longest serving member of the Disabled Persons Protection Commission, or a designee, serve as the Chair of the Board, H128 proposes that an individual with no specific organizational ties shall be appointed by the Governor to serve as Chair. Not requiring the Chair to be from one specific organization or department increases the likelihood of having a Chairperson who has a diverse background in self-determination practices potentially improving the outcomes of the Board. By making this change and continuing to include the individuals, families, and guardians on the Board who are already self-directing their services, a voice in how self-determination works within the Department of Developmental Services will continue to be present. In order to continually improve self-directed services, the participants who experience these services firsthand must be included in the implementation and evaluation processes.

Second, this bill proposes financial management services required to be involved in the self-determination process by the previous law, to have specific training on the different components of self-determination. If the financial management service is trained and understands what self-determination is, how it works, what are person-centered plans and why self-determination is important, they will be able to improve the services they are providing to the participants.

¹ See Acts of 2014, Ch. 255 *An Act Relative to Real Lives*.
<https://malegislature.gov/Laws/SessionLaws/Acts/2014/Chapter255>.

Furthermore, they will be able to better assist participants in disbursing the funds of their individual budgets according to their person-centered plan.

Lastly, HB 128 states that “costs of the services of an independent facilitator shall be paid by the participant out of the participant's individual budget unless the participant chooses an authorized state employee to be the independent facilitator².” After analyzing this part of the bill, the Council is concerned that this will take away from the individual's choice. An individual will most likely choose the option that requires them to use no funds from their individual budget even if choosing a non-state employee to be an independent facilitator may be the better option for him or her. This indirectly takes away from the individual's choice, taking away from the original intent of Real Lives to maximize an individual's wants and needs to create a better service system for him or her.

Below are some thoughts from our Council Member Debbie Pierce that depict how important it is for her to have access to flexible supports in the community that change according to her schedule and needs. The passage of the original Real Lives legislation was very important to Debbie because it meant she would be able to tailor her supports to her life. H128 has the potential to strengthen the original Real Lives Law and improve Debbie's life:

“I live in Worcester, MA in my own apartment and work three days a week at a warehouse. I use both the Ride and the bus to travel around Worcester. I am a Department of Developmental Services client and receive 15 hours a month of staffing. My staff assists me with paying my bills, they take me to medical appointments and take me grocery shopping. I like to play bingo in my apartment building and I attend self-advocacy meetings. I love to shop at Wal-Mart and I enjoy going out for coffee. I am a lucky person. I am happy with my life. My staff helps me with things I need support with and this helps me to live in the community. Right now, 15 hours a month of staffing is barely enough hours for me. Most months I have a few doctors' appointments and it is hard to do everything with my staff I need to do outside of the doctor visits. It would be nice if I could increase my staff hours every month according to the number of doctor appointments I have. This would be better for me than having a set 15 hours a month that is not changed according to my busy schedule. I want my supports to be more flexible which I need some months.

This bill would allow me to choose who helps me in making these decisions. It would help me to save money in the process of choosing my supports because I need to use as much of my budget on supports as possible. This bill would also help me have people supporting me who understand self-determination, and know how to help get what I want.”

In summary, the Massachusetts Developmental Disabilities Council believes that HB 128 will have an overall positive impact on people with disabilities if it is passed. We appreciate the opportunity to educate Committee members about the bill and welcome the opportunity to schedule a follow up meeting with members if additional questions arise.

Sincerely,
Ashley McAnespie, Disability Policy Consultant
Massachusetts Developmental Disabilities Council

² See Acts of 2014, Ch. 255, §19, Ch. 19A (a). An independent facilitator “is a person selected and directed by the participant to assist in the development and execution of a person-centered plan and to assist the participant in making informed decisions about the participant's choices regarding self-determination.”